



Neuropathy Hope

Hope through caring, support, research, education, and empowerment

A newsletter for members of the
Pacific Chapter of The Neuropathy Association (PCNA) / Western Neuropathy Association (WNA)

February 2015

Issue 2

Volume 13

Program For Annual Conference

PCNA/WNA Support Groups

Rare Neuropathies Pose A Challenge For Diagnosis And Treatment

President's Message

Thinking Differently About Treating Neuropathic Pain

PN Literature Review

Alpha Lipoic Acid For Neuropathy

Vital Information From Speakers And Articles In PN News

Woodland September Notes

Davis October Notes

Canola Oil, Good Or Bad?

High Or Low Tolerance For Pain, It May Be In Your Genes

Once A Day Gabapentin

Pacific Chapter of The Neuropathy Association / Western Neuropathy Association
P.O. Box 276567
Sacramento, CA 95827-6567
877-622-6298
888-556-3356
info@pnhelp.org
www.pnhelp.org

PROGRAM FOR ANNUAL CONFERENCE, APRIL 22, 2014

Jelly Belly Factory Event Center, Fairfield, CA

9:30 AM	Registration and Morning Snacks
10:00	Conference Begins Announcements and Introductions
10:10	Keynote Speaker Dr. Kevin Sawchuk, Neurologist Kaiser Permanente Medical Center, Walnut Creek, CA
11:10	Break
11:20	Interactive Activity
12 NOON	Lunch
12:50 PM	Presentation by Blood Source Dr. Jeffrey Ralph, Neurologist, UC-San Francisco Medical Center
1:30	Closing Announcements and Door Prizes
2:30	Adjournment

Optional opportunity to go on a tour of the Jelly Belly Factory

RARE NEUROPATHIES POSE A CHALLENGE FOR DIAGNOSIS AND TREATMENT—BE YOUR OWN ADVOCATE

In the U.S., the Rare Disease Act of 2002 defines a rare (or orphan) disease as any disease or condition affecting less than 200,000 people (or about 1 in 1,500). Of the over 100+ different types of neuropathies impacting millions in the U.S. alone, there are several neuropathies that are considered rare diseases including hereditary neuropathies like Charcot-Marie Tooth (CMT), familial amyloidotic polyneuropathy (FAP), and familial amyloidotic cardiomyopathy (FAC), Lambert-Eaton Myasthenic Syndrome (or LEMS), sarcoidosis, Fabry's disease, adult polyglucosan body disease (APBD), multifocal motor neuropathy (MMN) and chronic inflammatory demyelinating polyneuropathy (CIDP) among others.

Because these neuropathies are rare (and rarely seen), diagnosis for many can be a difficult and drawn-out experience; many who have been successfully diagnosed have had to be their own patient advocate to achieve that diagnosis. Still, a diagnosis can hold the promise for improved care and the hope of therapies already available and

several more in development.

While diabetic peripheral neuropathy is what primarily comes to mind for many when discussing neuropathy, there are actually more than 100+ different types of neuropathies caused by a range of diseases and disorders. And approximately one third of all neuropathies are considered to be "idiopathic" or "of an unknown cause." For people with rare neuropathies – many of which can be extremely debilitating – the path to diagnosis can be an arduous journey which may still lead to an "idiopathic" diagnosis without the help of specialists trained to recognize these rarer neuropathies which can have symptoms mimicking other diseases and disorders...or which simply don't "fit" together. Being your own best advocate for a diagnosis becomes critical. Diagnosis offers the opportunity for hope as some of these rarer neuropathies now have new treatments either available or on the horizon...if you have a confirmed diagnosis. Used by permission of The Neuropathy Association

Roster of Our PCNA/WNA Information and Support Groups

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Please contact
your group leader
or check your
local paper to
find out about
the topic/speaker
for the upcoming
meeting.

Bev Anderson
Editor

Newsletter Design by

 Diane Blakley
Designs

CALIFORNIA

Alturas

For information call:
Bev Anderson (877) 622-6298

Antioch-Brentwood

3rd Wednesday, 2 PM
Antioch-Kaiser, Deer Valley
Watch for sign or check at desk.
Bev Anderson 877-622-6298

Auburn

1st Monday, 11 AM
Woodside Village MH Park
12155 Luther Road
Sharlene McCord (530) 878-8392

Bakersfield

3rd Wednesday, 1:30 PM
Stockdale Moose Lodge
905 S. Stine Rd..
David Wollard (661) 663-9406

Berkeley-Oakland

3rd Wed., 3-4 PM
North Berkeley Senior Center
1901 Hearst Ave.
Kathleen Nagel (510) 653-8625

Carmichael

2nd Tuesday, 1:30 PM
Eskaton
3939 Walnut Ave.
Karen Robison (916) 972-1632
*Call Karen before coming as it is a gated
community and sometimes the day/time
changes. She welcomes newcomers!*

Carmichael

3rd Thursday, 6 PM
Atria El Camino Gardens
2426 Garfield, Ave.
Tanysha Kaye (916) 488-5722

Castro Valley

2nd Wednesday, 1:30 PM
First Presbyterian Church
2490 Grove Way (next to Trader Joe)
Judson Leong (510) 581-6697

Clearlake

For information, call
Bev Anderson (877) 622-6298

Concord

3rd Thursday, 1:30 PM
First Christian Church
3039 Willow Pass Road
Wayne Korsinen (925)685-0953

Crescent City

For information call:
Bev Anderson (877) 622-6298

Davis

2nd Tuesday, 3:30-5:00 PM
Davis Senior Center
646 A Street
Mary Sprifke (530) 756-5102

Elk Grove

2nd Tuesday, 1 PM
Elk Grove Senior Center
8830 Sharkey Avenue
Roger White (916) 686-4719

Eureka

For information call:
Earlene (707) 496-3625

Folsom

3rd Monday, 1:00 PM- odd numbered months
Journey Church
450 Blue Ravine Rd.
Bev Anderson (877) 622-6298

Fort Bragg

For information call:
Betty Adams (707) 964-3327

Fresno

3rd Tuesday, 11:00 AM
Denny's Restaurant
1110 East Shaw
Marvin Arnold (559) 226-9466

Garberville

For information call:
Bev Anderson (877) 622-6298

Grass Valley

2nd Monday, 1:30 PM
GV United Methodist Church
236 S. Church Street
Salli Hearn (530) 268-1017

Jackson

For information, call
Bev Anderson (877) 622-6298

Lakeport

For information call
Mito Shiraki (707) 245-7605

Lincoln

Thurs., Oct. 23, 1:00 PM
Bev Anderson (877) 622-6298

Livermore

4th Tuesday, 10 AM
Heritage Estates
900 E. Stanley Blvd.
Sandra Grafrath (925) 443-6655

Madera

For information, call
Bev Anderson (877) 622-6298

Merced

2nd Thursday, 1 PM
Central Presbyterian Church
1920 Canal Street
(The Hoffmeiser Center across the
street from the church)
Larry Frice (209) 358-2045

Modesto

3rd Monday, 10:30 AM
Trinity United Presbyterian Church
1600 Carver Rd., Rm. 503
Monte Schrader (209) 531-3838

Monterey

3rd Wed., 10:30 AM-odd numbered months
First Presbyterian Church
501 El Dorado Street
Don & Ann Trout (831) 372-6959

Napa

1st Thursday, 2 PM
Napa Senior Center
1500 Jefferson Street
Ron Patrick (707) 257-2343
bonjournapa@hotmail.com

Oxnard

For information call:
Bev Anderson (877) 622-6298

Placerville

For information, call
Bev Anderson (877) 622-6298

Quincy

1st Thursday, 1 PM
Our Savior Lutheran Church
298 High St.
Stacey Harrison (530) 283-3702

Redding

For information call:
Tiger Michiels (530) 246-4933

Redwood City

4th Tuesday, 1 PM
Sequoia Hospital Health and
Wellness Center
749 Brewster Avenue
Stan Pashote (510) 490-4456

Roseville

2nd Wednesday, 1PM-odd numbered months
Sierra Point Sr. Res.
5161 Foothills Blvd.
Carol Brosk (916) 531-2752

Sacramento

3rd Tuesday, 1:30 PM
Northminster Presby. Church
3235 Pope Street
Charles Moore (916) 485-7723

Salinas

Contact Bill Donovan
(831) 625-3407

San Francisco

4th Thursday, 10 AM
UC-San Francisco Med Ctr.
400 Parnassus Avenue
Amb. Care Ctr. 8th Flr., Rm A888
Y-Nhy (e nee) Duong
Nhy-y.duong@ucsf.edu

San Jose

3rd Saturday, 10:30 AM
O'Conner Hospital
2105 Forest Avenue
SJ DePaul Conf. Rm.
Stan Pashote (510) 490-4456

San Rafael

3rd Wednesday, 1 PM
Lutheran Church of the Resurrection
1100 Las Galinas Avenue
Scott Stokes (415) 246-9156

Santa Barbara

4th Saturday, 10AM-odd numbered months
The First Methodist Church
Garden & Anapamu
Shirley Hopper (805) 689-5939

Santa Cruz

3rd Wednesday, 1PM-odd numbered months
Trinity Presbyterian Church
420 Melrose Avenue
Mary Ann Leer (831) 477-1239
maleer@comcast.net

President's Message

By Bev Anderson



Now is a good time to register for the Annual Conference on April 22, 2015. I hope you will join me in doing so this month. You can send your check for \$20 to PCNA, P.O. Box 276567, Sacramento, CA 95827-6567 or go on line to www.pnhelp.org and pay by credit card. All attending Board members also pays the fee for the conference. We are starting to sign up exhibitors which will add another flavor to the conference.

Last month, we published Dr. Donovan's article about a speaker at the Monterey Neuropathy Support Group where he is assistant leader. This month, I'm including several descriptions of group meetings and some other material from PN News, the Yolo County newsletter that Mary Sprifke edits and sends out by e-mail or standard mail 10 months a year. They take off July and August. It is an outstanding newsletter and you can find it on our website at www.pnhelp.org if you would like to read back issues. If you would like to contribute to the Yolo Groups to encourage the newsletter, you can send your contribution to the PCNA office earmarked for the Davis Support Group subaccount. Your contribution is tax deductible and will be listed on your annual report of giving that we send out. Once in a while I borrow some material from the PN News. The information about Acetyl-L-Carnitine (ALC) could save a life. It was touted for some while and recently a man in one group that brought it up at almost every meeting that we should be taking it died suddenly about a year ago. I don't know the cause of his death. If there is an interesting speaker in your group, please have someone take notes and send in a report. I'd be delighted to include it. Just don't get too lengthy. I reserve the right to edit it.

- Continued on page 7

PCNA/WNA Information and Support Groups – continued from page 2

Santa Maria

2nd Tuesday, 12:00 Noon
Elwin Mussel Senior Center
510 Park Street
Wanda (805) 938-1086
Mary (805) 344-6845

Santa Rosa

1st Thursday, 10:30 AM
Santa Rosa Senior Center
704 Bennett Valley Road
Larry Metzger (707) 541-6776

Sonoma

For information, call
Bev Anderson (877) 622-62988

Sonora

For information, call
Bev Anderson (877) 622-6298

Stockton

For information, call
Bev Anderson (877) 622-6298

Susanville

For information call:
Bev Anderson (877) 622-6298

Thousand Oaks Region

For information, call
Bev Anderson (877) 622-62988

Truckee

For information call:
Bev Anderson (877) 622-6298

Tulare-Visalia

For information call
Bev Anderson (877) 622-6298

Turlock

3rd Monday, 1 PM
Covenant Village Adm. Bldg. Classroom
2125 N. Olive St.
Joanne Waters (209) 634-0683

Ukiah

Last Tuesday, 5:30 PM
North Coast Opportunities (NCO)
413 N. State St.
Shirley Blattner (707) 621-0208
Carole Hester (707) 972-2795

Walnut Creek

4th Friday, 10 AM
Rossmoor, Hillside Clubhouse
Las Trampas Room
David Woods (925) 287-8100

West Sacramento

No meeting until new leader is found
Sandra Vinson (916) 372-6093
slvins11@gmail.com

Woodland

No meeting until new Leadership Team forms.
Elizabeth Chaudhry (530) 661-3859

Yreka

For information call
Bev Anderson (877) 622-6298

Yuba City-Marysville

2nd Tuesday, 10:30 AM
St. Andrew Presbyterian Church
1390 Franklin Rd.
(next to Winco Shopping Center)
Ken Lux (530) 673-3479

NEVADA

Reno-Sparks

For information call
Bev Anderson (877) 622-6298

OREGON

Brookings

For information, call
Robert Levine (541) 469-4075

Grant's Pass

3rd Wednesday, 10:30 AM
First Christian Church
305 SW H Street
Carol Smith (541) 955-4995

Medford

For information, call
Bev Anderson (877) 622-62988

Portland

For information call
Joe Mozena (503) 505-0692 or
Bev Anderson (877) 622-6298

Salem

3rd Monday, 6:30 PM
Community Health Education Center
Salem Hospital Campus, Bldg. D
890 Oak Street SE
Michael (503) 857-3508
newsfosalem@gmail.com

Start a support group in your
area: Contact Bev Anderson at
(877) 622-6298 or info@pnhelp.org

Help With Health Care Challenges

If the number is not in
your area, call the one
listed and ask for the
right number.

Medicare

www.Medicare.gov

•••

The Affordable Health Care Act

For current
information go to
www.HealthCare.gov

•••

HICAP

Health Insurance Counseling

for seniors and people
with disabilities.

www.cahealthadvocates.org
/HICAP/

Call (800) 434-0222 to
ask a question or to
make an appointment.

•••

Health Rights Hotline

Serving Placer, El
Dorado, Yolo, &
Sacramento Counties,
regardless where you
receive your health
coverage.

Tollfree (888) 354-4474
or TDD (916) 551-2180.

In Sacramento,
(916) 551-2100.
www.hrh.org.

•••

HMO Help Center

Assistance
24 hours a day, seven
days a week.
(888) HMO-2219
or (877) 688-9891 TDD

•••

DRA's Health

Access Project Free
publications about the
health care, insurance
rights and concerns of
people with disabilities
and serious health
conditions. For more
information, go to
<http://dralegal.org/> and
click on "Projects".

THINKING DIFFERENTLY ABOUT TREATING NEUROPATHIC PAIN

By Corey W. Hunter, MD, April 25, 2012

Pain, in any form, can present a difficult challenge for even the most astute pain physician. The complexity of treating neuropathic or nerve pain stems from a variety of reasons, ranging from the lack of an obvious source of the pain to the inability of the patients to explain what ails them, to an arduous history that was poorly managed with the wrong medications, allowing the pain to progress to a seemingly unmanageable state. Many people with neuropathic pain are often given escalating doses of opioids in a fleeting attempt to control their discomfort; it is not until much later that they will seek the help of a pain management specialist. As many can attest, opioids are rarely a good choice for the sole treatment of neuropathic pain. Neuropathic pain medications, which include certain antidepressants and antiepileptics (indicated for specific types of neuropathic pain), are rarely discussed with these patients in the early stages, and, unfortunately, are often first mentioned late in the disease's progression. Moreover, the mere suggestion of these medications for the treatment of neuropathic pain is often met with confusion and even mistrust toward the doctor by patients not appropriately counseled by their physicians, leading to reactions like: "I'm not depressed," or "I'm not crazy, I just need a higher dose of my medication...my pain is a '15' on a scale of 1 to 10!"

The growing neuropathic pain epidemic has created an uphill battle for both patients and the physicians trying to help them. Whereas nociceptive pain can usually be pinpointed to an actual event (e.g., pain resulting from a broken arm), neuropathic pain can be vague and nondescript in nature.

For many physicians, there is no sense of need to tease out the details from the ambiguity; a prescription is provided for an opioid-pain killer and the patient is sent home. Not only will the discomfort most likely continue, but now the patient is subjected to an unnecessary risk for prescription drug dependency—another epidemic unto itself. Understanding what neuropathic pain is and how it might present itself are the first and most important things to consider. If you believe your pain symptoms are neuropathic, you should ask your doctor these questions:

- My pain is not getting better; could this be neuropathic pain?
- The medications I am taking are not helping; could this be neuropathic pain?
- Are these the appropriate medications for treating neuropathic pain?
- How much experience or training do you have in treating neuropathic pain? Could I get a second opinion?
- Is the medication you are giving me potentially addictive? What else should I know about these medications?
- Can you explain how anti-depressants and anti-epileptics work to treat neuropathic pain?

Waiting to get appropriate care makes neuropathic pain harder to treat. However, even severe cases of neuropathic pain can be managed effectively by an informed patient with the proper therapies.

Corey W. Hunter is a pain management specialist and served on The Neuropathy Association's Neuropathic Pain Management Medical Advisory Council. (Used with permission of The Neuropathy Association)

PERIPHERAL NEUROPATHY LITERATURE REVIEW

By William B. Donovan, M.D.

We can access the National Library of Medicine (**NLM**) to obtain information on peripheral neuropathy (**PN**). There are over 100 medical articles a month written on PN.

I review these references and select articles that would appear to be most interesting to us neuropathy sufferers. This is the link to **PubMed** that will take us to the **NLM**: www.ncbi.nlm.nih.gov/sites/entrez

If you are reading this article on the computer, just click on the above link to go there. If you are reading the print edition of the newsletter, type this link into the address bar of the browser on a computer. If you don't know how, get a librarian or friend to help you.

After you get to **PubMed**, you will see a line that says "**Search PubMed**" followed by "**for**" and a space. Every article in the **NLM** is given a **PMID**, an eight digit identification number. I will give you **PMID** numbers of the selected articles. Type the **PMID** into the space after the "**for**" and click on "**Go**" at the end of the space, or press the ENTER key on your keyboard. You will then see a one paragraph abstract of the article appear, as well as links to related articles.

This month's PMIDs:

- 22717465 Pre- and post-testing of patients with diabetic peripheral neuropathy subjected to a 10-week aerobic and strengthening exercise program revealed significant reduction of pain; increased intraepidermal nerve fiber branching (on skin biopsy); and decreased neuropathic symptoms.
- 22809652 A Cleveland Clinic review of the opioid buprenorphine (Subutex®) supports its use as a "first line analgesic" for the treatment of cancer and neuropathic pain. Its advantages include: less tolerance and constipation, less respiratory depression and cognitive impairment, fewer side effects, and greater safety and effectiveness with the elderly.
- 22810071 A detailed review of the differential diagnosis and treatment of immune-mediated neuropathies, both involving the myelin sheath and neural vasculature. The article compares the findings in Guillain-Barre, the various demyelinating neuropathies, myasthenia gravis, botulism poliomyelitis, tick paralysis, toxic states and carcinomatosis, as well as hematologic conditions that can underlie these neuropathies.
- 22893563 Diabetic peripheral neuropathic pain which is responsive to duloxetine (Cymbalta®) showed a drop in pain score in proportion to the level of baseline score.

ALPHA LIPOIC ACID FOR NEUROPATHY

Alpha lipoic acid has been found to be effective in treating neuropathy. Alpha lipoic acid is a fatty acid that can be found inside every cell of the human body. This fatty acid plays a very important role in the conversion of glucose into energy. It is also a powerful antioxidant that can neutralize the free radicals and thus prevent the oxidative damage of the cells and tissues of the body. Today, alpha lipoic acid is known for its effectiveness in treating neuropathy which is caused by the damage of the peripheral nerves.

Numbness and tingling in hands and feet, burning pain, and muscle weakness are some of the common symptoms of peripheral neuropathy, and these symptoms can be alleviated to a great extent with the help of alpha lipoic acid. Peripheral neuropathy therefore, can be treated with alpha lipoic acid. Let's find out about alpha lipoic acid for neuropathy, as well as alpha lipoic acid benefits and side effects in the following paragraphs of this article.

Alpha Lipoic Acid for Neuropathy

As has been mentioned already, alpha lipoic acid is a potent antioxidant and as an antioxidant, alpha lipoic acid can neutralize both water and fat soluble free radicals. It can reach all parts of the nerve cells and protect them from the harmful effects of the free radicals. Many researchers have suggested that nerve disease may be caused by the free radical damage. So, alpha lipoic acid can provide protection against nerve damage caused by the free radicals and thus help to treat neuropathy or peripheral neuropathy.

Peripheral neuropathy can be associated with several conditions including diabetes, chemotherapy, alcoholism, Lyme disease, and nutritional deficiency. Alpha lipoic acid can prove effective for treating both diabetic neuropathy and chemotherapy related neuropathy. Chemotherapy related neuropathy is mainly caused by drugs such as paclitaxel, bevacizumab, oxaliplatin, and gemcitabine. The symptoms of chemotherapy related neuropathy are similar to the diabetic neuropathy and these can also be alleviated with the help of alpha lipoic acid.

Though there are certain drugs that can

be used for neuropathy treatment, they cause several side effects. Alpha lipoic acid on the other hand, can help to treat neuropathy without causing many side effects. One study has found that an oral dose of 600 mg. of alpha lipoic acid for neuropathy has considerably reduced the symptoms of this condition. Another study, which was released in 2002 from the Journal of Clinical Oncology, revealed that more than half of the patients taking the chemotherapy drug oxaliplatin experienced less symptoms of neuropathy after they were treated with alpha lipoic acid.

Side Effects of Alpha Lipoic Acid

A high dosage of alpha lipoic acid can cause a few side effects like, nausea and upset stomach, and reduce the level of minerals in the body. Headaches, skin rash, muscle cramps and low level of blood sugar can be some other alpha lipoic acid side effects. So, diabetic people using alpha lipoic acid should maintain caution, and monitor their blood sugar levels regularly while taking the supplements of alpha lipoic acid. The safety of using alpha lipoic acid in pregnant and nursing women has not been established until recently. Patients should talk to their health care provider before considering taking supplements of alpha lipoic acid for neuropathy treatment.

Children should not be given the supplements of alpha lipoic acid, while individuals having liver and kidney disease should consult their physicians regarding the use of these supplements for the treatment of neuropathy.

So, alpha lipoic acid can have really important benefits for the treatment of neuropathy. As far as its dosage is concerned, a dosage of 20 to 60 mg. per day is recommended for the general use of alpha lipoic acid for antioxidant support while 300-600 mg. per day is the recommended alpha lipoic acid dosage for neuropathy and diabetes. The use of alpha lipoic acid for neuropathy can have some additional benefits, especially for the skin. It is believed that this fatty acid can protect the skin from free radicals and it is a strong antioxidant. Alpha lipoic acid benefits for skin include a reduction in the appearance of wrinkles and fine lines, and improved skin tone and texture.

By Chandramita Bora Used by permission of www.Buzzle.com. Intelligent Life on the Web

DISCOUNTS FOR PCNA MEMBERS

The following companies or individuals have agreed to give PCNA a discount to PCNA members. Give them a call or visit. If you choose to purchase the service or wares of any on this list, pull out your PCNA Membership Card and claim the discount.

Anodyne Therapy
Infrared Light Therapy equipment - **\$50 off Model Freedom 300 (single leg at a time) and \$50 discount on Model 120 that does both legs at the same time.** Contact: 800-521-6664 or www.anodynetherapy.com

HealthLight Infrared Light Therapy equipment - **10% off Single Boot System and Dual boot system.** Contact: 888-395-3040 or www.healthlight.us

Auburn
The Footpath
825 Lincoln Way
(530) 885-2091
www.footpathshoes.com
PCNA Discount: 10% off the regular price shoes.

Elk Grove
Shoes That Fit
8649 Elk Grove Blvd.
(916) 686-1050
PCNA Discount: 20% off the regular price shoes.

Fortuna
Strehl's Family Shoes & Repair
Corner of 12th & Main
1155 Main Street
(707) 725-2610
Marilyn Strehl, C.PED is a Certified Pedorthic
PCNA Discount: 10% off the regular price shoes.

Sacramento
Midtown Comfort Shoes
3400 Folsom Blvd.
(916) 731-4400
PCNA discount: 15% on the regular price.

- Continued on page 6

DISCOUNTS FOR PCNA MEMBERS

Continued from page 5

West Sacramento Beverly's Never Just Haircuts and Lilly' Nails
2007 W. Capitol Ave, West Hair-(916) 372-5606
Nails-(916) 346-8342
PCNA discount: 10% off the regular price.

Neuropathy Support Formula

(1-888-840-7142) is a supplement that a sizable number of people are taking and reporting it has helped them. The company gives members of PCNA a discount and free shipping. The 30-day supply is \$40 (normally \$49.97). It can be auto-shipped monthly for the same. A 3-month supply via auto-ship is \$95.00. They also have a Nerve Repair Optimizer that is available for \$20 with free shipping. Marsha, the manager, said that if anyone wants more information about the product, they can call and ask for her. If she is not readily available, leave your number and she will call you back.

Free DVD on "Coping with Chronic Neuropathy", introduced by Dominick Spatafora of the NAF and endorsed by major university neurologists, is available by contacting the Neuropathy Support Network at www.neuropathysupportnetwork.org/order-neuropathy-dvd.html

Additional Discounts

Do you know a business that might offer our members a discount? Tell them that they will be listed each month in our newsletter and on our website so our members will know of their generosity and patronize their business. Call (877) 622-6298 or e-mail info@pnhelp.org.

We'll mail an agreement form to the business, and once we have it, we'll add them to this list.

VITAL INFORMATION FROM SPEAKERS AND ARTICLES IN PN NEWS (Yolo County)

One reader requested more clarification about a warning printed in the April 2014 PN News. Dietician Monica Randel had warned us that Acetyl-L-Carnitine (ALC) "could damage the colon, which could lead to heart attacks" and she urged discussing using ALC with your doc-

tor. I spoke with her again and she clarified: "ALC does not directly damage the colon; there are some probiotics in the colon that process carnitine, producing a toxic gas that may lead to a heart attack." (Editor)

WOODLAND SEPTEMBER NOTES By Terri Newton

Our speaker for this meeting was physical therapist Carolyn Silan.

What can physical therapy do for you?

Increase muscle strength, balance, and coordination.

Tai Chi and diabetic neuropathy

Both can reduce neuropathy total symptom scores, including physical functioning, bodily pain, physical role limitations, emotional role limitations, and social functioning.

Weight-bearing vs. non-weight bearing exercise

Both will successfully increase some measure of muscle strength, physical function, and activity

without causing injury in an individual with diabetes mellitus and peripheral neuropathy.

Balance training benefits

Diabetic patients who experience peripheral neuropathy and balance problems can achieve better balance and stability through progressive balance training with emphasis on the anterior/posterior neuromuscular elements of stability. Ms. Silan also discussed TENS therapy and advised us to change activities frequently, such as

walking, swimming, etc. We also participated in some stretching and flexibility exercises and viewed the YouTube video "Understanding Pain: What to do about it in less than five minutes."

DAVIS OCTOBER NOTES The meeting was led by Charles Moore

We viewed the DVD by Dr. Peter Skaff. The DVD is an excellent summation of Peripheral Neuropathy in layman's language, but would be a great resource to share with your doctor too. Dr. Skaff used an outline form for his presentation.

What, exactly, is Peripheral Neuropathy? In short: Bad Nerves.

1. The body has three types of nerves: motor (to trigger our movement muscles), autonomic (to operate processes such as lungs, heart, digestion, bowel, blood vessels, and bladder), and sensory (to feel external stimuli).

2. Just as electric cords have wires on the inside; enclosed by insulation on the outside, our nerves have an axon in the center and the myelin sheath on the outside.

3. Symptoms • Numbness - no sensation • Altered sensation - electrical shocks, tingling, pins and needles, stabbing, stinging • Imbalance - unsteady, dizzy • Weakness - nerves controlling muscles atrophy • Autonomic systems can be affected.

4. Common Causes • Diabetes and pre-Diabetes (50% of PN cases worldwide) • Alcoholism

(second most common in the US) • Vitamin deficiencies (B12, B6, Folate) Age impacts ability to process vitamins. • Medications - cancer, heart, antibiotics • Metabolic, including thyroid deficiency, high cholesterol, kidney dysfunction • Heredity • Compression - pinched nerve • Idiopathic (unknown origin accounts for about 1/3 of the cases).

5. Less Common Causes • Long-term infection, e.g., shingles, Lyme disease • HIV and AIDS • Cancer • Vasculitis • Lupus, CIDP, RA (autoimmune) • Gastrointestinal See the doctor if your symptoms are persistent. Your own, personal description of your symptoms is very important since the doctor uses your information, coupled with a physical exam and lab tests, to begin the search for a cause.

6. Tests should include: 2-hour oral glucose tolerance, thyroid, nerve conduction, electromorphography, nerve conduction velocity, imaging, and B12 levels.

This DVD can be ordered from PCNA, P.O. Box 276567, Sacramento, CA 95827-6567 for \$5.00. The DVD by Jeffrey Ralph M.D., also \$5.00, is a good choice to give to doctors, too.

CANOLA OIL, GOOD OR BAD?

By Dr. Cate Shanahan (Excerpts) <http://authoritynutrition.com/canola-oil-good-or-bad/>

Back in the day, oil called rapeseed was often used for industrial purposes. It was cheap to produce, but people couldn't eat it because it contained some unfavorable substances:

1. Erucic acid: a fatty acid that caused heart damage in some rat studies

2. Glucosinolates: bitter compounds that made the oil taste bad. Some Canadian scientists wanted to turn rapeseed oil into edible oil, so they used selective breeding techniques to "create" seeds that contained less of these harmful, bitter substances. Canola is actually not a unique plant. It's just a name for rapeseeds that have been bred to be low in these undesirable compounds. Today, about 90% of the world's canola crop is genetically modified.

A toxic solvent called hexane is used to extract the oil from the seeds. Trace amounts of hexane have sometimes been found in cooking oils. Artificial Trans fats are incredibly harmful and associated with many serious diseases, especially heart disease... the biggest killer in the world. However, keep in mind that cold-pressed and organic canola oil has not gone through the same process and won't contain so many oxidized fats or Trans fats.

Bottom Line: Canola oil is made with a highly unnatural processing method that involves high heat, deodorization, and the toxic solvent hexane. Significant amounts of Trans fats are formed during this process. Like most highly refined oils, canola oil is low in essential nutrients; however, it does contain a little bit of the fat-soluble vitamins E and K. A typical fatty acid composition of canola oil is: Saturated: 7%. Monounsaturated: 63%. Polyunsaturated: 28% (with Omega-6 and Omega-3 in a 2:1 ratio). (Keep in mind that the exact figures and ratios can vary between different batches.)

According to conventional wisdom, saturated fat is bad

and unsaturated fats are good, so according to that, the fatty acid composition is pretty much perfect. However, there are a few things that need to be mentioned here. Although saturated fat has been considered harmful in the past, several recent studies have shown that it really has nothing to do with heart disease. Therefore, the low saturated fat content of canola oil is completely irrelevant, although it does allow for some excellent marketing slogans. Canola oil is also high in monounsaturated fats, which are healthy. These are the fats found in large amounts in olive oil.

Really, if you want a good source of Omega-3s, then eat some fatty fish once or twice a week, or supplement with fish oil.

Therefore, I would take the cholesterol lowering effects of canola oil with a grain of salt. It is likely that consuming it has some other detrimental effect that outweighs the benefits of lowered cholesterol. Seed and vegetable oils are generally unhealthy. Conventionally produced rapeseed/canola oil is no exception. If you can get your hands on organic, cold-pressed canola oil, then it won't be as high in oxidized fats and trans fats,

I definitely wouldn't make it a large percentage of calories and I would definitely NOT cook with it, as it is still too high in polyunsaturated fats. Conventional canola oil (which is what most people are consuming) is low in nutrients, high in oxidized Omega-6 fats, high in Trans fats and the Omega-3s happen to be in an inefficient form. Overall, canola oil is not as bad as other vegetable oils (like soybean oil), but it is still far from being healthy. You would do much better eating olive oil or coconut oil instead. If you want to learn more about which cooking oils to eat and which to avoid, then read this online article: [Healthy Cooking Oils – The Ultimate Guide at http://authoritynutrition.com/healthy-cooking-oils/](http://authoritynutrition.com/healthy-cooking-oils/)

President's Message – *Continued from page 3*

When you look at the list of support groups at the beginning of this newsletter, you will notice that some say "For information contact Bev Anderson" or some other person. Those are places we have met with a group of people or a group formed but didn't continue. We have members at each of these locations but are lacking a leadership team. Two or more people willing to lead a meeting at least six times a year is all it takes to reactivate it. If you can team with someone else to do this, we would rejoice. It takes people who like to be with others and are at ease in doing so. If you are a people person, this is the opportunity for you. The leadership team members don't have to have neuropathy, but be willing to learn about it. We provide information and materials.

Many thanks to all that have renewed their dues and/or made a donation in December and January. We are encouraged by the response. We hope that everyone whose dues are due now or later in the year will renew. During the year, we grow in membership. Then comes January when the majority of our members have their anniversary date and we see our membership numbers down again. Please remember that your local support group gets a portion of your dues so we all benefit when they come in.



Bev Anderson
President



The Pacific Chapter of The Neuropathy Association

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tax exempt corporation

P.O. Box 276567, Sacramento, CA 95827-6567

Call PCNA/WNA using our toll free phone numbers:

(877) 622-6298 • Email: info@pnhelp.org

• PN Information/Advice • Support Group Inquiries

(888) 556-3356 • Email: donnad@pnhelp.org

• Membership Information/Inquiries • Sponsorships
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go on line to www.pnhelp.org and pay by credit card.

IF YOU HAVE A HIGH OR LOW TOLERANCE FOR PAIN, IT MAY BE IN YOUR GENES

Researchers presented a paper at the May 3, 2014 American Academy of Neurology Annual Meeting indicating that they have identified genes linked to the level of pain a person feels. If doctors could check to see if these genes are present, they could know better the reason one patient may feel more pain than another. It also helps in the research on reasons for difference in pain responses and the perception of pain. Study author Dr. Tobore Onojighofia says, "Chronic pain can affect every other part of life. Finding genes that may play a role in pain perception could provide a target for developing new therapies and help physicians better understand their patients perceptions of pain."

Information about chronic pain may be found at www.aan.com/patients

ONCE A DAY GABAPENTIN

There is a type of gabapentin called gabapentin enacarbil that you take once a day. Dr. Yuen So says that you can talk to your doctor about it to see if it is right for you.



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Bev Anderson, Editor

P.O. Box 276567

Sacramento, CA 95827-6567

(877) 622-6298 • (888) 556-3356

info@pnhelp.org • www.pnhelp.org

PCNA Headquarters: donnad@pnhelp.org

Our mission is to provide support, information and referral to people with neuropathy and to those who care about them, to inform and connect with the health care community, and to support research.

Dues - \$30 a year

All contributions and dues are tax-deductible.

We are supported by dues-paying members, contributions by members and friends, and occasionally, small grants and fundraisers.

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